

Family Involvement in Rehabilitation: A Developmental Model

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Research Problem

The family has assumed an increasingly important role in the conceptualization of the course and treatment of schizophrenia. Psychosocial treatments that intervene at the environmental level to reduce stress, such as family interventions, have been shown to have a positive effect on the subsequent course of schizophrenic illness (Goldstein, et al., 1978; Falloon, et al., 1982; Leff et al., 1982, 1985; Falloon & Pederson, 1985; Hogarty et al., 1986, 1991; Tarrier, 1988; Randolph et al., 1994). Given the importance of the family in terms of their effect on the course of illness, the burden suffered, and their lack of satisfaction with existing treatment by professionals, it is critical to systematically investigate family involvement patterns and ultimately use the information to target treatment more effectively. The Clinical Research Services Panel of NIMH (1992) has recommended that the varying kinds and degrees of family involvement "should become an important variable in rehabilitation effectiveness research" (Attkisson, 1992, p. 601).

But several critical issues have impeded progress toward full understanding of family involvement in the course and psychosocial treatment of schizophrenia:

1- Family interventions have been conducted almost exclusively with individuals who were hospitalized or reside with their family. As a consequence, there are few cross-sectional studies and virtually no longitudinal data to characterize family interaction patterns for persons living in the community. Brekke and Mathiesen's (1995) study was one of the first to investigate the nature of family interaction in a sample of noninstitutionalized adults with schizophrenia. Results from this cross-sectional study found that higher levels of psychosocial functioning varied with the subjects' living situation, which suggests the need to address living situation as an important variable in psychosocial rehabilitation. Family support has only begun to be understood in terms of its value in improving outcomes (Glynn et al., 1993).

2- There are no existing comprehensive models to predict how family interaction patterns may change over the course of the illness; 3- Client characteristics, such as gender, ethnicity, and age, have been shown to be related to course of illness, but little is understood of their relationship to family involvement; 4- Research efforts must be directed toward understanding the relationship between intensive community-based

rehabilitative treatment and family involvement. In addition, the NIMH clinical services research panel on the severely and persistently mentally ill has recommended the use of analytic techniques that take into consideration the difficulties inherent in repeated measures of changing variables (Attkisson, 1992).

This study will establish patterns of parental contact for a sample of persons diagnosed with schizophrenia and participating in community-based rehabilitative treatment. The study will determine if systematic differences in pattern based on family residency, treatment type, gender, ethnicity, or age of onset are present. In addition, a developmental model based on individual, family, and illness processes (Rolland, 1994) will be adapted to the characteristics of schizophrenia. An initial test of one aspect of the model will determine if age, phase of illness, or the interaction of age and phase are significantly related to parental contact. The data will be analyzed with hierarchical linear modeling, a technique that preserves individual differences, yet permits analysis of group differences.

Research Questions

The specific aims of this research project were:

Aim 1(a) - To describe prospective change in the quantity and quality of parental involvement over a three-year period in an urban, ethnically diverse sample of community-based individuals diagnosed with schizophrenia.

Question 1(a): Concerning the whole sample, how does the quantity and quality of parental involvement change over time?

Aim 1(b) - To explore possible systematic differences in temporal patterns of parental involvement based on family residency.

Question 1 (b): Is the living situation of the subject associated with differences in the quantity and quality of parental involvement over time?

Aim 2 - To explore possible systematic differences in temporal patterns of parental involvement based on (a) participation in intensive, community-based rehabilitative treatment, (b) age of onset, (c) gender, or (d) ethnicity.

Question 2 (a): Are there differences in the quantity and quality of parental contact over time based on participation in intensive vs. non-intensive rehabilitative treatment?

Question 2 (b): Based on age of onset?

Question 2 (c): Based on gender?

Question 2 (d): Based on ethnicity?

Aim 3 - To test hypotheses based on the adaptation of Rolland's (1994) psychosocial developmental model. Hypotheses to be tested will help to determine if age, phase of illness, or the interaction of age and phase of illness are predictive of parental involvement over time.

Question 3 (a): Is age significant in predicting levels of parental contact in community-based individuals, based on normative age categories?

Question 3 (b): Is the phase of illness significant in predicting the level of contact for community-based individuals diagnosed with schizophrenia?

Question 3 (c): Is there a phase of illness X age-linked developmental stage interaction predictive of parental contact for community-based individuals?

Methodology

Subjects: This study was a secondary analysis of three years of prospective data collected on a sample of 172 persons diagnosed with schizophrenia. The parent study was a longitudinal quasi-experimental design that compared treatment outcomes of three community support programs (CSPs) and a low service intensity group. Data were collected on all subjects at baseline and at 6-month intervals for a total of three years. All subjects included in the study had a diagnosis of schizophrenia or schizoaffective disorder based on an initial screening by an admitting clinician from chart review and interview data. This screening was followed by a face-to-face interview by a trained clinician using the Schedule for Affective Disorders and Schizophrenia (SADS; Endicott & Spitzer, 1978).

Measures: Data were gathered with face-to-face interviews using the Community Adjustment Form (CAF) (Test et al., 1991), a semi-structured interview with the subject that focuses on objective behaviors or events over specific time periods. Four psychosocial variables were used to measure family involvement. The first measured the quantity of parental contact, defined as the frequency of face-to-face or telephone contacts between the subject and parents in the prior two-month period prior to the interview. Three additional variables measured the quality of parental involvement. 1-The quality of family relationships was measured with the family relationships item from the Role Functioning Scale (RFS) (McPheeters, 1984; Goodman, Sewell, Cooley et al., 1993). 2-The degree of satisfaction with family relationships was measured with the family relationships item from the Satisfaction with Life Scale (SWL) (Stein & Test, 1980). 3-The level of independence from family was measured with the family rating scale from the Social Adjustment Scale II (SASII; Western Psychiatric Institute, 1974).

Analysis: While many inadequacies that have plagued research on individual change have been identified (Rogosa, 1988; Willett, 1988; Collins, 1991), a potential solution is the growth or change curve approach (Rogosa, Brandt & Zimowski, 1982; Rogosa & Willett, 1985). The change curves for the current study were created using Hierarchical Linear Modeling (HLM/2L) software (Bryk & Raudenbush, 1994). The value of the procedure is evident in the ability of the analyses to reveal the amount, direction, and variation in change for each person in the study, while simultaneously providing optimal estimates of the population parameters at the group level. HLM was able to model the enormous individual variation present in the variables and also allowed hypothesis testing of the model.

Individual change is first modeled across time for each subject using least-squares regression. The result is a growth curve: a within-subject summary of change for each person over time. At level two, the parameter estimates obtained at level 1 are used as dependent variables in a new equation. Predictors of systematic change (covariates) become the independent variables. The individual curve parameters are then recomputed with weights that reflect the relative error of each phase.

Summary of Results

The first aim of the study was to document the changing patterns in the quantity and quality of parental involvement for a community-based sample of persons diagnosed with schizophrenia. One of the important findings regarding changes in parental contact was that there was wide individual variation over time. Subjects maintained a significant amount of contact with family (an average of 1.6 contacts per week) over the 3-year study period. The second important finding was that the mean change curves three of the four family involvement variables (amount of contact, the quality of family relationships, and the level of independence from family) were very similar in form and direction: a gradual increase over time that peaked around 18 months into the study, and gradually decreased over the remainder of the study. The study is one of the first systematic longitudinal efforts made to explore family involvement for diagnosed individuals who live apart from family, the majority of severely mentally ill persons. An important and unexpected finding was that subjects reported a significant overall increase in the level of independence from family for the first 18 months of the study, even during periods of increasing contact with their parents. This finding held for both the entire sample and for the subsample who did not reside with family (the "No Family Living" or NFL group).

The second aim was to determine if living situation, type of treatment, gender, ethnicity, and age of onset were systematically related to parental involvement. In these covariate analyses, the first significant finding was that the NFL group had little change over time in the quality of their family relationships, while those moving in and out of the home showed a pattern of gradual increase, followed by a gradual decrease. Second, the self-reported satisfaction with family relationships modestly but steadily declined for those who spent any days of the three-year period living with parents. Third, a surprising finding was that the quantity and quality of parental contact do not appear to be related to the intensity of the psychosocial rehabilitation program, nor with the subject's gender.

The covariate analyses revealed that the quality of family relationships was significantly different based on the age of onset of illness. For both the entire sample and the NFL group, earlier onset was significantly related to increasingly better family relationships. Earlier onset was also significantly related to declining levels of independence from family for the entire sample.

The third aim of the study was to test hypotheses based on a longitudinal psychosocial developmental model. As expected, the observed fluctuations in parental

contact did not conform to the normative age expectations. The patterns of change in parental contact were very similar for all age groups, with a gradual increase which peaked around 18 months, then decreased. The changes based on the phase of illness, while not significantly different from each other, revealed that the mid-phase was very stable in terms of parental contact, while the early and late phases showed increases followed by declines. The interaction of age and phase was complex, but statistically nonsignificant. Those aged 28-39 and in the early phase of illness, and those aged 40-59 and in the mid-phase of illness had very different patterns of change from all other combinations of age and phase.

Implications for Social Work Practice

The psychosocial treatment of those diagnosed with schizophrenia offers social workers the opportunity to develop ongoing relationships with family members, as well as with the diagnosed individual. But the complexity of the illness and the changing needs of the individual and family over time are often overwhelming to both the clinician and family. Parents are anxious about their ability to serve as effective caregivers, how best to help their adult offspring, and their own changing capabilities. It has been suggested that interventions should be targeted to the caregiver's age and ability, as well as to the phase of their child's illness (Cook, et al., 1994).

This study offers the first empirical evidence of the changing patterns of parental involvement, and the relationship between the changing variables. Social workers, whether clinicians, researchers, or administrators, now have evidence of the magnitude and nature of family involvement for a community-based sample. These results provide the foundation for further understanding of the continuing role of the family in the lives of their family member. Social workers may use the data to help families understand the fluctuating nature of the quantity and quality of family involvement. The results concerning those living outside the family home as particularly enlightening, as little research attention has focused on their ongoing family relationships. It is evident from these results that there is substantial, ongoing contact and involvement with family members. For this sample, there was an 18-month period of increasing independence that coincided with increasing contact and improved quality of family relationships. The decline in the three variables after initial improvement may signal an important point for intervention efforts by social workers and family members. Understanding the patterns and monitoring changes will alert clinicians to potential difficulties, and help to prepare family members for change.

The developmental model also has value for social workers as they attempt to provide information to individuals and families. Researchers have emphasized the need for a developmental perspective that would allow individuals and families to be viewed in a normative context (GAP, 1992). This study addresses the need for more complete models that help to conceptualize the complexity of psychosocial factors in schizophrenia. The study presents an initial test of hypotheses based on individual and family developmental

processes. This is an important step as we attempt to move beyond description of the illness, and determine to what extent normal developmental processes are present.

The fluctuations in the amount of parental contact did not conform to normative age expectations, but more closely followed predictions based on the phase of the illness. For clinicians, individuals, and families, it is important to have information that may predict deterioration in family relationships, and to acknowledge that it may be cyclical rather than a permanent state. In this way, a variation of intervention intensity or a different use of family may be used to promote improved quality of life over time. The results from this study will help clinicians and families to join their efforts and visualize a beginning general structure of family involvement over time, allowing individual and family differences to be mapped and modified according to individual and family differences in order to improve psychosocial outcomes.

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